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ABSTRACT

The issue presents three articles on autism. The first, "Autism--A Professional Challenge" by Carl Smith, introduces the other two articles and very briefly defines autism as "severe communication and behavior disorders that become manifest during the early stages of childhood development and that are characterized by a severely disabling inability to understand, communicate, learn, and participate in social relationships." The second article, "Autism--A Parent's Perspective" by Connie Toland, outlines various concerns of parents of autistic children pertaining to the search for appropriate programs to meet their children's needs. The third article, "University of Iowa's Program for Autistic Youngsters" by Sandy Furlong, briefly describes a program for autistic-type children operated by Child Psychiatry Services at the University of Iowa in Iowa City. (DIS)

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IOWA PERSPECTIVE

News of Programs for Emotionally Disabled and Chronically Disruptive Students

Iowa Department of Public Instruction

January, 1978

Autism -- A Professional Challenge

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Consultant
Emotional Disabilities and Chronically Disruptive

Educational programming for youngsters appropriately identified as "autistic" or "autistic-like" is an area new to many of us. As with other "emerging" areas in special education, we are being called on to develop educational programs with little information being provided.

This issue of *Perspective* contains two articles dealing with this area. Ms. Toland's article outlines many of the concerns I have heard voiced by parents of these youngsters pertaining to the search for appropriate programs to meet their children's needs.

Ms. Furlong's article briefly describes the program for autistic type children operated by Child Psychiatry Services at the University of Iowa in Iowa City. Other programs serving this population of handicapped pupils are found in our public schools.

The term "autism" is not specifically found in our *Rules of Special Education* (1977). But this is **not** intended to imply that such youngsters are not considered handicapped in our state When asked to define this population, I typically refer to the definition as referred to in Chapter 444.12 of the Iowa Code:

> **"Autistic children" means persons, regardless of age, with severe communication and behavior disorders that become manifest during the early stages of childhood development and that are characterized by a severely disabling inability to understand, communicate, learn and participate in social relationships. "Autistic children" includes but is not limited to those persons afflicted by infantile autism, profound aphasia and childhood psychosis.**

It is our responsibility to develop appropriate special education programs for this population of handicapped pupils. I hope that these two articles serve as a stimulus for doing so.

Autism -- A Parent's Perspective

by
Ms. Connie Toland
Quad-Cities Society
for Autistic Children

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One thing we all want is **progress**, which demands more information. I feel that the facilitation of progress in an area such as autism is helped through a specific, concentrated focus on this condition as a distinct, unique disorder. One goal of this article is to help in this concentrated force, and therefore resist the too frequent tendency to lump autism together with other problem areas because it has certain features or symptoms which appear similar to other handicapping areas.

The National Society for Autistic Children (NSAC) was founded in 1965 by psychologist and prominent autism authority, Bernard Rimland. Aside from his academic credentials, Dr. Rimland is the father of an autistic child. Following his leadership, many other bright, energetic, as well as frustrated and desperate parents, were rapidly drawn into the movement. Many of these people, in addition to having helped to develop the national movement, have made outstanding contributions to the professional literature surrounding autism. All of this implies the beginnings of an aroused public awareness and conscience and a gradual turning of professional attention and interest to this heretofore sadly neglected area of concern.

Ruth Sullivan, an early president of NSAC and one of our hardest working and most respected officials, stated in the 1975 *Newsletter of the International Society for Autistic Children:*

> **Struggling individual families of autistic children in the United States, still mired in the incredible problems of trying to get adequate help must find it hard to**

believe that conditions, generally, are improving. However, when one lifts his eyes to the national picture, bright patches are seen over the land. The turning of events is like the beginning of a fever breaking in a life-threatening infectious illness. At the peak of the threat, one prays only for survival. Once that becomes a real possibility, one then prays for full recovery. In a way, the fever has already begun to break. Most professionals in the health field can now spell the word, "autism." Quite a few can describe it, and a growing number have a good understanding of the condition and how to cope with it. It was only a dozen years ago that the local Mental Health Association in my city suggested, when I called for information, that I contact the Institute of Art and History.

I might say parenthetically, that although this may seem a bit ludicrous to Iowans who have begun to develop a bit of familiarity with the problem of autism, I can assure you that what may have happened in this regard on the East Coast, or the West Coast (or Huntington), a dozen years ago, can still be replicated in this part of the Midwest today. Our local chapter, the Quad-Cities Society, has been in existence almost four years--long enough to be taken somewhat seriously (though not funded)--and has wound up on an increasing number of mailing lists of various local agencies. We receive such things as questionnaires related to surveys they may be taking or planning; or they may make inquiries regarding our interest in such widely varying areas as: abused or neglected children, incest, employment training, or our projected need for counselors and so on. But whatever--the overriding impression created is one of a vast deficit of understanding regarding the nature and needs of the autistic population. And this is not the general public, of course, but various health and welfare-related organizations, including occasionally a mental health association, or mental health center.

Thus, it can be painfully apparent to certain chapters around the country (like ours!) that improvement on a national level doesn't necessarily translate into an immediate beneficial change in a given local area or region. Still, even in our part of the Midwest, the "assault on the vast ignorance, apathy, misinformation, unfair laws, cruel administrative policies, and general hopelessness about the disorder" has had an impact; and, to pick up Ruth Sullivan's medical metaphor: "The fever has begun to break."

This state of affairs, however, does indeed represent only an **initial** hopeful sign, rather than anything resembling even a measure of recovery. The initial gains, as reflected in enhanced public awareness, mandatory education laws, new biochemical and neurological research approaches, have created an awareness that reaching such a stage, however encouraging, brings in its wake new challenges, problems, issues, and decision-making requirements.

A restive attitude seems to be developing on the part of many parents--a nagging feeling that more must be learned; that public school placement, per se, has not really solved the problem, or necessarily resulted in an appropriate or satisfactory program; that the most difficult children are still not being served; that no significant amount of attention is yet being given to long-range needs.

Much of the concern seems to be reflected in stepped-up advocacy and "watchdogging" activities. Our national newsletters seem to increasingly reflect the enormous effort that is being put forth to keep up with legislative developments, regulations, guidelines, grants, as many of our national officials become increasingly entangled in the bureaucratic jungle. I do not want for a moment to appear to diminish the importance of such activities--far from it!

Many of our people who are currently involved in political activity are some of the same ones to whom such enormous credit is due for their heroic and brilliant efforts in the early days of the movement when it would have taken all kinds of courage and ingenuity to have moved a **stone**--much less a mountain! We urgently need them and their constant policing, unearthing and "gadflying," which, it seems, must never cease if we are to overcome.

However, the new challenges posed by some of the emerging problems seem to call for an increased amount of grass roots input if the right directions are to be taken to assure optimal benefit to **all** the autistic children, not just a fragmented few. And so, perhaps it behooves the rest of us who have developed strong convictions about these matters to get into the fray a bit and speak our minds.

One of the fundamental issues generated by the new education mandates, and the increased flow of public money into the realm of therapy and education for autistic children revolves around how best to spend the money. This directly relates to the types of programs and facilities which should be developed to best serve this population. Many parents, naively assuming that once legislation and money were assured their problems would be solved, left implementation in the hands of the professional establishment. However, growing expressions of dissatisfaction in many quarters suggest that some parents are facing what many of us have experienced for years.

Specifically, it is no accident that there has been such a long delay in the provision of services for this type of child who presents such a formidable challenge. Such a challenge has caused many professional workers to hastily and consistently look the other way or to take a firmly fatalistic stance as represented by admonitions such as, "not enough is known; it is just too difficult; there is **nothing** we can do." How could anyone realistically expect that legislation and appropriation of money would suddenly transformed the situation, where hardly a shred of understanding, knowledge or expertise was available?

In the face of these facts, parents' own activities and input into this major decision area would seem to be enormously important--not only because they are not influenced by having an empire they wish to protect or expand, but also because they are closest to the children. They also have the most first-hand knowledge--and certainly the deepest personal concern, unmatched by that of any outsider, however sympathetic and dedicated. But, at the present time, this logic will probably not prevail, or have much influence in shaping the course of events. This is reflected in the recent "normalizing" and "mainstreaming" mania which has permeated the world of social planners and special educators.

These "normalizing" principles were initially conceived of and espoused by those concerned with the mentally retarded. These people were convinced of the importance of placing this type of handicapped person, in both living and working arrangements, in direct contact with so-called "normal" peers. The spreading of this influence, manifested in some cases by combining all types of handicapped youngsters in one program, have resulted in such concepts as "least restrictive

environment" and "least segregated setting" as almost a panacea for all handicapped pupils. Apparently the de-labeling fervor, which has been part of this trend, works greatly to the advantage of those administratively responsible by simplifying program planning, effecting economy, and possibly in expanding empires or departments. We are all reminded in effect, that **"Big is Better!"**

Quite recently, however, the normalizing and mainstreaming principle, philosophy, fad, or whatever, has begun to be challenged as it relates to psychotic, or other seriously behavior-disturbed children. The **"Parents Speak"** section of the most recent *Journal of Autism and Childhood Schizophrenia* was devoted to this topic, containing articles and comments, most of which were critical and full of repeated references to the difficulties encountered when attempting to apply a rigid system to these children. Gary B. Mesibov, Ph.D., of the Division for Disorders of Development and Learning of the Biological Sciences Research Center, University of North Carolina, in his significant article, "Implications of the Normalization Principle for Psychotic Children," states:

> **Because this group of psychotic children represents an extreme group in terms of their deviance from the normal population, the problem of integrating them into society is a most difficult one. . . . Because of their severe behavioral difficulties and extreme needs, psychotic children, even more than other groups of handicapped children, are in need of very specialized and individualized instruction.**

The point is made by Ruth Sullivan, in a comment in the same series, that there is, of course, an enormous range in severity in the population Mesibov calls psychotic. However, it is my impression that there are more similarities than differences between the higher functioning and lower functioning autistic youngsters. At any rate, mainstreaming for the better-functioning, and less behavior-disturbed, should it prevail, should not preclude development of a different type of program and setting--"segregated" although it may be.

A small therapeutic and educational day center, geared to coping expertly with serious behavioral handicaps while offering high quality special education programs, could provide closer to normal living for this kind of very special child than many parents would have ever dreamed. We should remember that autism is a true handicap, just as surely as poor eyesight or a faulty limb. Such a structure allows the youngster to live in his own natural home, with his natural parents, aided and supported by a community gradually made helpful and understanding via well-planned and specific publicity efforts. Let's hope that the provocative *Journal* expressions cited above will bring more discussion and attention to this matter; a concept so important for parents of behaviorally disordered children.

Closely related, and of almost equal concern, is the matter of immediate and long-range planning for those of adolescent age and beyond. More and more frequently the question is being asked: "What can we do for our **older** children?"

I would like to attempt to answer that. For one thing, we can stop taking the easy way out by going along with those who place them in inappropriate workshop situations, obviously designed for another type of handicap. For another thing, we can quit putting so much emphasis on **chronological age**, per se. If a youngster has been developing increased responsiveness and rapport; if better communication is continuing to develop; if a measure of adaptation can still be instilled; if there are ample opportunities to make use of higher-level abilities; if activities to help improve functioning on a practical level are provided; if a program instills a sense of worth and encourages a zest for participation--then why worry about changing programs, directions or philosophy because a certain date has occurred on the calendar?

As Mrs. Sybil Elgar, director of Somerset Court, a senior school for autistic children in England, pointed out at a recent NSAC meeting, that most of these children have a maturational lag in certain areas which slowly improves with the passage of time. This permits achievement and benefit from various social and educational offerings **far beyond** the usual cut-off time. And, as she said, to cut them off--just because of their chronological age, at a time when they may finally be able to enjoy or progress in some of these areas, is wasteful of previous time and effort, as well as most tragic for them and their families.

As one who has had first-hand experience with this kind of tragedy, I am aware of the supreme importance of **enlightening** all of you regarding the meaninglessness of chronological age with autistic or other psychotic-type children. Where the developmental pattern is so unusual that near-genius level abilities may coexist with infantile emotional reactions; where baffling paradoxes and variations in response and performance pose a continual perplexity and where subtle and elusive learning problems seem to hold back and often obscure what Bernard Rimland has referred to as "the provocative nearness of an unusual cognitive potential," it seems like **utter folly** to anxiously focus on **age**.

Fortunately, there are beginnings of what promise to be appropriate and excellent combined day and residential facilities in this country for the older autistic children. An Ohio teacher is developing a school and program modeled along the lines of Mrs. Elgar's Somerset Court. Two well-established day schools for autistic children are now developing residential components for the older students. It is only a bare beginning, but it could be the start of a trend, which if continued, would help assure the best possible future for the student-residents in the very special atmosphere which only those who really understand autistic children can provide.

This brings me to the matter of personnel. Parents are keenly perceptive here and display almost instinctive judgment in sensing which people are "right" for their unusual and difficult youngsters. Personal qualities such as a special sensitivity, a zest for the work, a temperament, a certain attitude, although difficult to specifically define, all blend into the person we say "has it!" This combination usually has nothing to do with the number of degrees held or courses taken or whether or not there is a certificate for us to scrutinize. While I fully recognize the necessity for standards and certification, I would be less than candid if I did not make the point that many of us concerned about the welfare of our disturbed children have had experiences in the past which make us feel that securing the **right kind** of people is of overwhelming importance. In fact, this is probably the single most important challenge facing public education, if there is any hope of its beginning to meet the needs of autistic children.

Although I do not believe that our National Society has given this fact enough emphasis, it is true that one of the most important personnel resources rests within the parents themselves. In fact, the incomparable problems and difficulties dictate intensive parent participation if there is to be any chance of significant improvement. As Ivar Lovaas, well-known pioneer in behavior modification work with autistic children, concluded several years ago, "There is no way to go about this other than through the parents. The only way these kids can be taught is by parents who can be with them all their waking hours. Professionals don't even make a dent." This may be a slight overstatement and, to be fair, parents often feel as if **they** don't make a dent either. However, the attitude and philosophy represented by such a statement in its inference to the **magnitude** of the problem and the need for a really **in-depth** and **prolonged** attack is surely eminently correct.

I was delighted that at a recent meeting held in Iowa, one of the main speakers was Dr. Eric Schopler. Since the founding of his famous TEACH Project in North Carolina a number of years ago, Dr. Schopler has made outstanding contributions to the cause of autism through his thoughtful writing and dissemination of important information and philosophy.

But perhaps what is unique and most valuable about Dr. Schopler's contribution is his bold and forthright dedication to the principle of parent **Status** (capital "S" I believe); to the actual implementation of direct, active parent involvement as therapists and teachers of their own autistic children. And, imagine this; he regularly uses parents in the classroom, where, as he described it, "the mystique of professional superiority was largely disspelled, and the caste system abolished."

Unfortunately, this idea has apparently not gained wide acceptance beyond rhetoric or tokenism, but both parent and professional leadership is greatly needed to see that parents **have** and **accept** a bigger piece of the action. Of course there are different degrees of proficiency and interest among parents; and, naturally, there will always be extenuating circumstances in some cases. But this is no reason to discard the whole idea. With so much to be done, with so much to be learned, with **excellence** the imperative--how can we afford the luxury of permitting this valuable resource to be wasted?

Although education therapy often seems to command most of the attention, let no one underestimate the parents' avid interest in research--especially in the continued search for some kind of safe, effective chemo- or nutritive therapy to help alleviate at least the most severe behavioral symptoms and perhaps contribute to better integration and functioning. Although we realize that the so-called orthomolecular approach, as initiated by Linus Pauling, and picked up by Bernard Rimland (who conducted a nationwide megavitamin study in which many children of NSAC parents participated) does not find favor with the medical profession in general, I have yet to find a **parent** who does not get enthusiastic about this type of exploration. We find the theory, at least **plausible** and therefore worthy of continued investigation.

In 1974, neurologist Mary Coleman, with a team of biochemists, conducted a pioneering study to obtain possible leads on biochemical factors related to autism. This nationwide study, sponsored by NSAC, utilized Rimland's diagnostic information and included almost 100 children from around the country. The parents cooperated for preliminary urine and blood sample mailings and then eagerly trekked to Washington D.C. in the summer of 1974 to complete the major part of the study. Most of you in medicine must be well aware of Dr. Coleman's volume, *The Autistic Syndromes*, which contains a full report of her important study. This study furnished enough leads to keep plenty of people busy for a long time.

In connection with our high interest in nutritive therapy or other biochemical approaches, some of us have become interested in the Iowa Schizophrenia Association which periodically sponsors speakers in Iowa who have been working in this field. We think it is appropriate that NSAC's honorary board chairman for 1977, actress Joan Woodward, is also involved with the Huxley Institute for Biosocial Research, which attempts to recruit physicians for specialized training.

Of course, we recognize that there are many other research approaches besides biochemistry, including neurological and educational approaches. However the latter area is not receiving the attention it should. Unfortunately, public education is not geared to this kind of endeavor. In any event, NSAC attempts to constantly encourage and keep abreast of all that is occurring in the research area.

In closing, I would like to say that the value of empirical findings should not be underestimated in all of this. Parents who work closely with their own children, and thus have an in-depth understanding of them, are well-equipped to make a significant contribution to the research effort by the development of interesting leads, as many of us already have done--in such areas as sensory-integrative, speech and language, symbolic abilities, and concrete relationships. These take the form of endless, intriguing, puzzling, exasperating, FASCINATING questions. We are looking to the hardiest of you in medicine, psychology, and education to help us answer them.

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University of Iowa's Program for Autistic Youngsters

by
Sandy Furlong
Coordinator - Autism Program
University of Iowa

Child Psychiatry Service at the University of Iowa has an inpatient evaluation and short-term treatment program for autistic children. Since the program began three years ago, the autism team has worked with almost 60 children ranging in age from 3 to 19. The autism program consists of a six to eight week stay in Iowa City during which time behavior modification programs are developed to increase the child's adaptive behaviors and decrease his undesirable behaviors. These programs are taught to the parents during a series of classes and during individual sessions between a family and the team working with the child.

After a child's discharge from the unit, the team continues to follow the child's progress at home and in school. Should problems arise in implementing the programs, team members are available to consult with parents and teachers over the telephone and by going to the child's home or school. In some cases, children have been readmitted to the program for further evaluation after a year or more and in a few cases children have been readmitted during a crisis.

The program at Child Psychiatry stresses a behavior management and skill teaching approach. Drugs are seldom prescribed as a method of controlling behavior. Fewer than ten percent of the children are treated with drugs.

Children in the program receive a comprehensive medical evaluation. The children typically receive a thorough speech, language and hearing evaluation, a detailed neurologic exam, metabolic screening tests, blood and urine analyses and an EEG. When indicated, additional tests are run.

Each child admitted to the program is assigned to a nurse. The nurse is responsible for establishing a care plan which specifies behavioral approaches to the problem behaviors identified by the parents and teachers. Throughout the day all staff members who come in contact with a child are working on the problems and skills identified by the parents and the team. All staff members are responsible for knowing and applying the procedures specified in the care plan. Care plans are written down on 5x8 inch cards and are available in the nursing station at all times.

The children's day begins about 7 a.m. with breakfast served about 7:45 a.m. Much valuable training in self-help skills (toileting, dressing, washing, etc.) takes place between arising and breakfast. Before school starts at 9 a.m., the children brush their teeth and straighten their rooms. The classroom teacher starts school with a half-hour music period followed by a half-hour during which the occupational therapists supervise activities designed to develop fine motor skills and sensory integration. From 10 a.m. to 10:15 a.m. the children have juice and cookies, one of the most important language training periods during the morning. For the next 45 minutes, the classroom teacher conducts individual activities designed to build academic and cognitive skills. From 11 a.m. until lunch at 11:45 a.m., activities therapists are in charge of programs such as simple games, crafts and field trips, designed to develop gross motor and social skills. A rest period follows lunch. Then during the afternoon, a group school activity is followed by one-to-one work with various team members.

The children's learning goes on after the "school day" ends and on the weekends. The psychiatric nursing staff uses this time to simulate family living situations, thus seeing firsthand the problems parents have noted as major concerns. From their seven-day-a-week, 24-hour-a-day contact with autistic children, the team members can quickly assess and start work on problems that are limiting the child's adjustment in the community.

The children in the autism program vary widely in their ability level. Over half of the children function in the moderate range of retardation or below (a score of 50 or less on a standardized intelligence test). Less than 20 per cent function in the normal range. About half of the children have no speech. Among the children who do have speech, many have only a few words, or echolalic, perseverative speech. Many of the children are not toilet trained. Two of the most commonly identified target behaviors are screaming and tantrums (84% of the children) and bizarre speech, play or mannerisms (96% of the children).

The outlook for autistic children has not been good. Follow-up studies indicate that about 60% of autistic children are institutionalized by the time they reach adolescence.

One study investigated reasons families chose to institutionalize their autistic child and isolated the following factors: 1) a lack of continuing professional support; 2) the realization in the child's adolescence that the mental retardation was going to continue to be a limiting factor in the child's adjustment; 3) difficulty finding school programs for autistic adolescents.

The autism program staff hopes that the combination of intensive short-term treatment, parent training, long-term follow-up and close cooperation and coordination with public school programs will decrease the likelihood that a family will choose to institutionalize their autistic child.

Most children admitted to the autism program are first seen in the outpatient clinic at Child Psychiatry. If it seems that the child would benefit from the program and the family is in favor of it, arrangements can be made to enroll the child in the upcoming program. Autistic children are admitted to the inpatient unit in groups of four to six for the six-to-eight week sessions. Referrals to the autism program come from teachers, physicians, psychologists, social service agencies and parents themselves.

The first step in referring a child is to call Rita Engels or Mary Ellen Einsphar at 319/353-5958. Some of the characteristics of autistic children include delayed and/or disturbed language (parrot-like speech, perseverative questions or statements), disinterest in people and surroundings, resistance to change in routine, unusual interest in inanimate objects and sustained odd play (spinning objects, flicking paper).

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